



Advocacy Action Network

*Kentucky Mental Health Coalition ♦ Kentucky Medicaid Consortium
Kentuckians for Health Care Reform ♦ United 874K Disabilities Coalition*

October 8, 2016

Department of Health & Human Services
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Dear Madam or Sir,

RE: Proposed Medicaid 1115 Waiver – Kentucky HEALTH

On behalf of the coalitions and organizations represented by the Advocacy Action Network, I am submitting our collective comments regarding Kentucky's proposed Medicaid 1115 Waiver – Kentucky HEALTH. We participated in all three of the public hearings in Kentucky on this issue, as well as submitting written comments for Governor Bevin and his Administration's consideration. We urge the federal authorities to carefully review all of the feedback that they receive and to give strong consideration as to whether this proposed waiver moves coverage, access, benefits and health improvement forward in Kentucky.

I have attached a sheet at the end of these comments which describes the coalitions gathered under the Advocacy Action Network (AAN) umbrella. As you can see from their descriptions, the organizations and their members, as well as individuals associated with the various coalitions, have as their goal improving the health of all Kentuckians, with a particular emphasis on those who are most vulnerable...those with disabilities of any kind, but particularly with behavioral health issues, and those without access to care.

AAN has been engaged in health care reform since the early 1990's and has tried to be an active and contributing member of any and all discussions initiated by various Administrations, legislative bodies, task forces or community forums which have as their goal the improved health and quality of life of Kentuckians. Our members and their organizations have spawned other working groups, committees, organizations and even coalitions to carry on that work. So, we bring to the table many, many years of activity and a wide range of input to advocate for and to strengthen services and supports, access to quality health care, the full continuum of behavioral health services, consumer/patient-centered care and the elimination of barriers and disparities. With that background in mind, we bring to you these comments:

- The Kentucky HEALTH waiver's goal is to improve health outcomes for all the Kentuckians which it serves.

We absolutely share that same goal. However, the Administration has repeatedly stated that the current Medicaid Expansion has failed "to move the needle" on improving health in Kentucky. We see the starting point quite differently. Medicaid Expansion has been good for Kentucky's health. It has provided health care access to nearly 500,000 Kentuckians who were previously uninsured and without health care, many for a long time. And Kentuckians have

120 Sears Avenue, Suite 212 ♦ Louisville, KY 40207

Phone: (502) 894-0222 ♦ Toll Free: (877) 894-0222 ♦ Fax: (502) 894-0635

kyadvocacy@gmail.com ♦ www.AdvocacyAction.net

taken advantage of their coverage in record numbers to access preventive care, screenings, teeth cleanings, mental health services and follow-up care. Kentucky's overall health ranking among the states has risen by 3 places. While we would all agree that we still have significant health challenges, Kentucky is healthier since Medicaid Expansion. This improvement in the health of Kentuckians must be maintained!

There are many contributing factors to Kentucky's poor health status, and sadly, there is no simple cure. Kentucky's healthcare problems will not be fully addressed until we tackle the social determinants of health, particularly poverty. With poverty comes substandard or no housing, little or no access to nutritious foods, neighborhoods or communities with polluted air and no place to exercise, etc. Kentuckians also struggle with significant lack of education, illiteracy, and geographical and racial inequities. All of these will need to be addressed to catapult Kentucky's health forward; in the meantime, we must concentrate on coverage and access to care.

- The Kentucky HEALTH waiver will maintain Medicaid Expansion in the Commonwealth.

Once again, we are in agreement with the Administration that Medicaid Expansion should be maintained in the Commonwealth. We believe, however, that coverage and access without barriers are critical elements of Medicaid Expansion that must be maintained. There is no doubt that providing Kentuckians with access to health care – physical, behavioral, dental and vision – is one of the requirements for “moving the needle” on our significant health problems. It is not the only factor needed to improve health, but it is a necessary factor. Health care access without barriers is foundational.

The proposed 1115 waiver puts in place many roadblocks and barriers to Kentuckians keeping the Medicaid coverage and access that they have now, and being able to get the health care services that they need. More than forty years of research, beginning with the Rand Corporation studies in the 1970's, plus experience from many other states, have demonstrated that cost-sharing requirements will reduce the number of individuals who will have and maintain coverage. And without coverage, there is no access. We recommend that there be no premiums for those in Medicaid Expansion. If premiums are to be charged, they should not be on an escalating scale which feels like taxation for being poor. We also request that there be a mechanism for determining instances where there is a hardship situation, to waive or reduce premiums, rather than to suffer a loss of benefits.

Maintaining coverage and access is more difficult when retroactive eligibility is removed, as is being proposed by the Administration. Particularly in the behavioral health arena, continuity of care is critical if members are to maintain their treatment regimen and be able to move toward recovery and more productive lives. Retroactive eligibility must be restored to the program!

- The Kentucky HEALTH waiver also has a goal of engaging Kentuckians in the Medicaid Expansion program in their health and in their communities.

Again, we are in agreement with the goals here, but we disagree with the premised starting point and with the methods of getting there. Let's look at the nearly 500,000 Kentuckians who have enrolled in the Medicaid Expansion to date. They are concerned about their health and many have already taken actions to improve it, as seen in the jump in preventative care and screenings, and the increased number of healthcare visits. Furthermore, the majority of these Kentuckians in the Medicaid Expansion are working, or are care-givers or students.

These individuals in the Medicaid Expansion population are already making significant investments in themselves and in their families. Unfortunately, those who are employed are being paid low wages; they do not have access to employer-sponsored health care or cannot afford what is offered. Those who are caregivers may not have a labelled “dependent” to care for, but they are being pressed into daily service for a spouse, grandchildren, or aging parents in need of support and care.

The proposed waiver would place a significant burden on these individuals in the form of a monthly premium requirement which would escalate over time. This approach fails to recognize that they are already working or are engaged in meaningful activity. It is as if a penalty is being imposed on them for being “working poor”. And the penalty for failing to pay the monthly premium is potentially catastrophic in terms of their health. They would be locked out from care for a six month period. That is too long to go without treatment and medication and will result in deterioration of health and increased use of emergency rooms for problems that can be managed with regular visits to a primary care provider and medications. Rigid denial of care cannot improve an individual’s health, or the state’s. The lock-out provision must be removed!

The psychological literature is replete with studies that demonstrate that positive reinforcement (aka, the carrot) is more effective as a behavior change agent than is negative reinforcement (aka, the stick). We urge the Administration to rethink their approach to behavior change and take a much more positive approach in the proposal. Punishments or penalties should be removed from the program and replaced with positive goal and rewards.

- The Kentucky HEALTH waiver sets out changes in the current program to assure the sustainability of Medicaid and of Medicaid Expansion.

We are certainly in agreement with the Administration that Medicaid Expansion needs to be “sustainable” in order for it to continue. We disagree with the premise that it is not. Medicaid Expansion has brought in more than \$3B in federal dollars since its inception to pay for health care delivery. Expansion has created at least 10,000 (some would posit more) health care jobs in Kentucky. Long-established studies have found a “multiplier effect” of Medicaid dollars into a state’s economy, most often set at \$7 to \$1. Even taking a much more conservative figure of \$1 of federal money generating a return of \$3.50 in state revenue, Kentucky has seen tremendous financial benefit from the Medicaid Expansion.

The approach taken in the waiver to reduce Medicaid Expansion costs appears to rest in a greatly-reduced number of Kentuckians who would be covered by the program. This is very worrisome. Cost-savings cannot be built on the backs of an increasing number of dis-enrolled or uninsured Kentuckians. True cost-savings in the immediate timeframe will come from building efficiencies into the program, in early detection and intervention, less use of the ER, and better care coordination. True cost-savings in the long term will require health system transformation. In the meantime, it would seem to be a bargain for Kentucky to buy \$1’s worth of health care for 5 or 7 or 10 cents. There should be no reduction in the numbers of Kentuckians covered by the program!

- The Kentucky HEALTH waiver fashions Medicaid Expansion like commercial insurance to teach Kentuckians how to be insured under employer-based plans.

The Administration’s goal here is an interesting one, and one not typically found in Medicaid programs. We wonder how realistic it is in Kentucky, where jobs are scarce...particularly jobs that pay a living wage and have the option of employer-sponsored coverage at an affordable

price. It seems that if these jobs were already available, that more Kentuckians who currently need Medicaid Expansion for their health coverage would be working in those jobs. We would also point out that the commercial health insurers are in business to make a profit, not necessarily to improve the health outcomes of their covered lives.

- The 1115 waiver proposal is clearly inclusive of the full range of behavioral health services.

Kentucky's behavioral health community has long been active in advocating for the full range of services and supports for all Kentuckians who are dealing with these issues. Our advocacy goals have been greatly bolstered by the Affordable Care Act which mandated significant improvements in behavioral health, requiring all coverage plans – Medicaid and private market – to include the full range of behavioral health diagnoses and treatment...and to provide these services at parity or equality with physical health care. We are pleased that the proposed waiver keeps these mandated services in place for all who are included in the waiver. Kentucky has significant mental illness and substance use disorders which need to be treated. We greatly appreciate the Administration's strong commitment to including and maintaining the current range of behavioral health services now available in Kentucky to Medicaid members.

- In addition, the waiver proposes a new treatment approach, made possible by utilizing the IMD Exclusion, to create a number of inpatient substance use disorder (SUD) treatment programs in the Commonwealth.

The additional inpatient or residential services which may be accessed with the relaxation of the IMD exclusion are much-needed across the Commonwealth. We had questioned the Administration as to whether Kentuckians with co-occurring mental illness and SUD would be able to get the help that they need and that clarification has not been specifically written into the waiver proposal. We are also aware that the proposed program will concentrate on the 54 counties at highest risk for SUD, Hepatitis C and HIV as identified by the CDC. We agree that this is a good start...but it is only a start.

We question where the funding for these expanded services will be found, and are concerned that already-existing programs of behavioral health services will lose funding in order to provide the state match for the IMD exclusion for inpatient and residential treatment. There is no doubt that Kentucky is in the midst of an epidemic of opioid and heroin use which cries out to be addressed. And clearly, there is a need for more inpatient, residential and IOP programs in the state. In light of SUD being the #1 public health issue in Kentucky, we urge the Administration to pursue this IMD waiver program regardless of the status of the overall proposed Medicaid 1115 waiver. That being said, we caution the Administration to be sure that it has funding sources to open these new services.

Later in these comments, we note the barriers to continued coverage and therefore, access, which the waiver proposal puts into place. These barriers will likely cause individuals who need this expanded SUD treatment to lose their continuing access to these services, disrupting their progress to full recovery.

- It excludes the vulnerable populations of children and pregnant women from any changes in Medicaid benefits or in the way that Medicaid currently works for them.

We agree with the Administration that these vulnerable populations of children and pregnant women should be able to maintain their current Medicaid status, eligibility and benefits...all

without any cost-sharing or other requirements imposed upon them. We had questioned the Administration in the initial proposal about the inclusion of foster children and youth up to age 26. We are pleased that the revised waiver proposal clearly indicates that these populations are clearly addressed, and are not affected in any way by the proposed waiver.

There has been some question about when the “pregnant woman” designation ends for an individual postpartum. We request that this issue be clarified in the waiver, as well as a clarification about whether the woman then goes into the dependent caregiver category and for how long. All parents deserve assurance that they have coverage and access without barriers, as the research is clear that their health is a determining factor in the health of their children.

- The waiver attempts to define a category for the “medically frail” and treats individuals in this category differently from those who are in the “able-bodied” category of Medicaid members.

While we applaud the retention of behavioral health benefits and the potential increase in SUD treatment opportunities, if appropriately funded, we are extremely concerned about this proposed category of persons deemed to be “medically frail”. While there has been communication that this category would include those with Serious Mental Illness (SMI), Substance Use Disorders (SUD), other disabilities that interfere with a task of daily living, those receiving SSI, and those receiving SSDI, the exact definition and the methodology for applying that definition are not specifically described. We asked in our initial comments to the Administration that the definition be clarified with more specific language and process. This has not been done, and the resulting uncertainty and confusion are alarming many Kentuckians who might fall into this category.

One aspect of the “medically frail” categorization is the inclusion of individuals who receive SSDI, making them eligible to be Medicaid members. A number of these individuals have chronic behavioral health conditions, and this will allow them access to services that are needed if they are to be in recovery. However, we again raise the question about funding for this new Medicaid population...where will the funding come from? We are concerned that funding may be shifted from services currently-available to Medicaid members to pay for this new population of members.

Words and descriptions matter and many Kentuckians are uncomfortable with the label “medically frail.” We have heard from Medicaid members who are behavioral health consumers and others with disabilities that they do not consider themselves “medically frail” and don’t like having what seems to be a stigmatizing and pejorative term applied to them. There is also the very concerning issue of whether this definition would also include the 7,000 – 8,000 Kentuckians who are potentially eligible for one of the 1915C waivers, but are on a waiting list for an open waiver slot.

With regard to making the determination of “medically frail”, we queried all five (5) of the MCOs, asking how many of their members would be classified as “medically frail”. All of them indicated that they did not currently use that terminology, nor did they have that categorization, and would need much more guidance and directions from DMS in order to be able to make that categorization of their members. The current waiver proposal includes a significant role for the MCOs in making this important determination. We believe that the individual members and their providers should have a significant role in making that determination, certainly greater than the MCOs.

These questions need to be answered: Who will make the determination of “medically frail”? On what basis will it be made? Can the determination be appealed by the Medicaid member or health care surrogate? What is the time-period for the determination? In the case of those with serious mental illness and/or with chronic substance use disorder, the severity of symptoms, the amount of resulting impairment of functioning, the timeframe for being in recovery (defined how?) are all variable and certainly subject to change – even dramatic change – over time. A person with a chronic SUD may be deemed “medically frail” before treatment is engaged, and during the course of treatment, may be very functional, and in recovery. If assessed at that point, is there a risk that the person will no longer meet the criteria for “medically frail” and be reclassified as “able-bodied”? If that occurs, the individual would then be subject to cost-sharing requirements, and work or volunteer requirements that cannot be met while still in a treatment program. If eligibility is lost at that point and with no retroactive eligibility, it is very likely that the significant gains made by the individual while in treatment will be completely lost!

AAN made extensive comments about the initial waiver proposal, pointing out the absurdity of requiring those deemed to be “medically frail” to pay a monthly premium for their coverage. We are very pleased that our voices were heard and that persons in this “medically frail” category are no longer being required to pay a monthly premium or co-pays, if the premium is not paid. This change recognizes the extent of disability, the likelihood that these individuals would not have the wherewithal to make such payments, and the need to maintain access to needed services and supports for this vulnerable population. We applaud the Administration for dropping all cost-sharing requirements for those Medicaid members who are determined to be in the “medically frail” category.

➤ Focus on the “able-bodied” in the Medicaid Expansion

For those other Medicaid members who are not children or foster youth, not pregnant women, and not “medically frail” – the bulk of those in the Medicaid Expansion – we assume that the Administration is terming them “able-bodied”. Again, these are Kentuckians who are, for the first time in many cases, having access to health care services and using them. We have heard from dental and vision providers, from allergists and asthma specialists, from primary care and behavioral health providers that these Medicaid members are engaged and are actively taking care of their health needs – physical, behavioral, oral and vision.

We know that health improves when the whole person is being treated. We have seen it in other states and in pockets of Kentucky where truly integrated care is taking place. This can only happen when the full range of benefits, dental and vision services, are available to all Kentuckians included in this waiver proposal. In a state plagued with toothlessness, cardiovascular disease and diabetes to name a few chronic conditions, the case has been strongly made to keep these critically important annual exams in the benefit package. It is a step backward and not forward toward improved health to do otherwise. All Medicaid members should have access to full dental and vision care as part of their benefit package. These should be restored, just as the Administration has restored allergy testing and private duty nursing.

We do note that the revised waiver maintains the discontinuation of non-emergency medical transportation for the Medicaid Expansion members. This seems to be extremely short-sighted in a state like Kentucky where there is little to no public transportation and where there are significant provider shortages, requiring travel to reach certain providers, especially specialists. We urge that non-emergency medical transportation be restored for all Medicaid members.

The current waiver proposal includes a very complex labyrinth of accounts which the Medicaid member will have to keep track of in order to keep their eligibility and to “purchase” additional needed benefits. This is a significantly greater burden than individuals with private insurance have in terms of eligibility and navigating their health care system. What is the administrative cost of setting up these accounts? What is the cost of monitoring compliance with the various requirements laid out in the waiver? Where does this funding come from...and couldn't those dollars be much more effectively invested in the health care system?

➤ KY HEALTH – Helping to Engage and Achieve Long Term Health

Yes, we absolutely share the Administration goal of long-term health for all Kentuckians! We appreciate having the opportunity to share our reactions, concerns, and recommendations with the federal agency. We believe that significant changes must be made in the proposed waiver in order to build on our successes and to move forward to create a more efficient and effective health care system for all Kentuckians. The waiver proposal takes us backwards on many fronts. The current Medicaid Expansion program assures that Kentuckians have access without barriers to the care they need to improve their health. The waiver must be revised to maintain that goal!

Sincerely,



Sheila A. Schuster, Ph.D.
Executive Director